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African American Women: The Face of HIV/AIDS in Washington, DC

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Abstract

In 2007, the estimated HIV and AIDS case rates among adult and adolescent African-American females in the United States was 60.6 per 100,000, as compared to 3.3 per 100,000 for adult and adolescent white American females. Women living with HIV or AIDS often face complex social problems that may inhibit them from accessing resources and healthcare services to assist them in coping with the disease. In-depth interviews and direct observations utilizing open-ended note taking were conducted at an HIV service provider's office to determine the unique needs that develop because of these complex social issues, specifically among HIV positive women of color in Washington, DC. Ethnographic methods were used to address the study's research questions among 10 women of different ages and backgrounds in group settings at a non-profit organization in Washington, DC. The qualitative results of the study indicate that the women dealt with a myriad of social and mental issues related to their diagnosis, such as fear of disclosure to family and friends. The study also revealed that the women were in dire need of mental health services to address their unresolved issues regarding their diagnosis. The implications of this research add to the growing body of literature on the mental and social health needs of women of color who are HIV positive.

Keywords

Qualitative Research, HIV/AIDS, African American Women, Health Disparities, Washington, DC, Social Services

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African American Women: The Face of HIV/AIDS in Washington, DC

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In 2007, the estimated HIV and AIDS case rates among adult and adolescent African-American females in the United States was 60.6 per 100,000, as compared to 3.3 per 100,000 for adult and adolescent white American females. Women living with HIV or AIDS often face complex social problems that may inhibit them from accessing resources and healthcare services to assist them in coping with the disease. In-depth interviews and direct observations utilizing open-ended note taking were conducted at an HIV service provider's office to determine the unique needs that develop because of these complex social issues, specifically among HIV positive women of color in Washington, DC. Ethnographic methods were used to address the study's research questions among 10 women of different ages and backgrounds in group settings at a non-profit organization in Washington, DC. The qualitative results of the study indicate that the women dealt with a myriad of social and mental issues related to their diagnosis, such as fear of disclosure to family and friends. The study also revealed that the women were in dire need of mental health services to address their unresolved issues regarding their diagnosis. The implications of this research add to the growing body of literature on the mental and social health needs of women of color who are HIV positive. Keywords: Qualitative Research, HIV/AIDS, African American Women, Health Disparities, Washington, DC, Social Services

HIV/AIDS is a major cause of morbidity and mortality among African-American women in the United States, and a study by Whitmore (2005) reported that HIV increasingly affects African-American women. Despite prevention efforts and advances in HIV treatment, African-American women are more likely to become infected with HIV or to die of AIDS than women of other races/ethnicities. African-American women are also more likely to have risk factors associated with HIV infection, which include poverty and at-risk partners such as men who have sex with men and women (MSMW) or injection drug users (Whitmore, 2005). Additionally, increasing proportions of new AIDS diagnoses among African-American women may reflect disparities in testing behaviors, whether and how African-American women seek healthcare, differential effects of HIV anti-retroviral therapy, and lack of early access to medical care and drug therapies (Leigh, 1993). In 2007, estimated HIV and AIDS case rates for African-American adolescent and adult females in the United States was 60.6 per 100,000, as compared to a rate of 3.3 per 100,000 for white adolescent and adult females, thus highlighting the burden of HIV experienced by African-American women (AVERT,

2009).

In general, women living with HIV or AIDS (WLWHA) may face a myriad of problems including, but not limited to, lack of childcare, misinformation regarding treatment options, lack of access to transportation, substance abuse and related recovery efforts, and a lack of stable and safe housing. Research suggests that specific barriers to the utilization of social and medical services for women in Washington, DC include a lack of insurance, current injection drug usage, and difficulty remembering appointments (DC Appleseed, 2005). In the lives of many HIV positive women, HIV is a disease that competes for resources that are already scarce, and in Washington, DC, unmet needs for basic necessities remains high among HIV infected persons with dependents and may disproportionately affect women (DC Appleseed, 2005). For example, when a woman must prioritize her spending, she may opt to take care of her basic needs, such as food, clothing, childcare, and housing, instead of paying for HIV/AIDS treatment and services. Additionally she may also postpone care due to lack of transportation to get back and forth to her appointments. These and other factors have been associated with a lack of access to care and usage of emergency departments for outpatient care. In addition to concerns related to access to resources, individuals who live with HIV/AIDS are at risk of internalizing the stigma associated with the disease, which may have adverse emotional effects if they do not have access to positive social networks and support (Buseh, 2006). Therefore, it is important to link HIV positive women to mental health services.

Though the academic literature (Adimora, 2005; Edwards, 2006) elucidates some of the factors, such as familial stress and stigma related to being HIV positive, as ways to explain African-American women's lack of service utilization, additional research is needed to determine the combined social and mental health services that women of color need. There is a dearth of public health research focused on the social service needs of African-American women living with HIV, as evidenced by a literature review of the subject. A lone article published in 2011 by DiStefano and Cayetano focused on the delivery of services for women with HIV/AIDS from the perspective of stigma and providers. The current research addresses the following research questions: (a) What barriers to social services do HIV positive African-American women experience in Washington, DC, (b) What mental health issues place African-American women in DC at increased risk for HIV, and (c) Do women with HIV face discrimination and issues rooted in stigma?

Methods

Ethnographic research methods were used to address the study's research questions and can include informal interviews, direct observation, and collective discussions with participants, all of which were performed during the research (Daly, 2007). According to Daly, "The primary aim of ethnography is to understand how things work from the perspective of the participants in that cultural setting...participant observation and interviews are the primary techniques or methods for understanding the way a culture works." Ethnographic methods were used to direct the course of the research study. Ethnography is rooted in the assumption that through prolonged interaction with participants, researchers are in the best position to understand the way

individual values, beliefs, motivations, and actions are expressed in and through culture (Daly 2007). Through the use of direct observation, I collected information in a group setting regarding stigma and issues of disclosure. Finally, each group session with the women lasted about two hours, and the individual interviews with the staff were on average about one hour long.

I'm working on this topic because it is one that is deeply personal to me. I would like to be an advocate for women of color who are HIV positive and want to tell their story. The literature captures their social needs such as housing, transportation, and childcare, but I wanted to examine the individual and community level factors that prevent women from accessing resources for themselves. These factors can be related to substance abuse, low educational attainment, or a host of other issues. While doing research for this paper I came across a startling fact from an article in the Washington Post. "In the District, black women represent 90 percent of women living with AIDS while making up only 62 percent of all women in the city, according to a report last year by the District's Health Department." (Fears, 2005). After reading this, I couldn't help but think that there had to be something else behind the numbers of such a high infection rate in African-American women. I endeavored to know more about the personal lives of these women, and the reasons behind noncompliance with medication, for example. For instance, if a woman is HIV positive and lives in a group home or a place where her family doesn't know her status, it's hard for her to take her medication consistently or at all. I would like to know more about issues of disclosure in HIV positive women and how that plays into health outcomes or social outcomes for the women.

Also of importance in my research is exactly what it means to be HIV positive to these women. Some of the women I interviewed during my time at The Women's Collective have developed coping skills and ways to deal with the processes around a positive diagnosis. I would like to use these women as a sounding board for other women who may be newly diagnosed and struggling with what it means to be HIV positive and a woman of color in Washington, DC. I'm curious to know if the women feel that they are discriminated against because they are HIV positive, or what an added relationship to substance abuse means for these women daily. Women who are recovering substance users face the fighting that daily battle as well and I'm sure it's emotionally draining. Another major strength that I utilized in my field research was bringing compassion, empathy, and sincerity to my conversations and interactions with the women. When I observed the support groups, I felt these women's stories, as if they were a part of my own family, or life. I realize that a lot of these women could easily be my mother, sister or friend. I put myself in the shoes of the women subconsciously, and wonder what my life would have been like if I had been physically or sexually abused, or a former or current drug user.

Participants

The women were recruited from an existing support group held at The Women's Collective and varied in age, education background, and income levels. Phone calls were made and flyers given to the women by case managers at The Women's Collective. The agency is a non-profit organization in Washington, DC. It was founded by an African-American woman with AIDS. Patricia Nalls, the founder and executive director, states "I

started the support group in my kitchen to meet some other women who had this disease and looked like me. I had no idea that there were other women who had this disease. I put flyers up in my doctor's office and gave my telephone number for women to call me. Soon, my phone was ringing off the hook.

I had no intention of doing this...if I **wanted** to do this it would not have happened...it became the thing I **needed** to do to save my life. I had to see my children grow; never in my wildest dreams did I think that I would be able to see this happen. I began preparing them for the worst. I did not want to live for me, I wanted to die but I couldn't because of my kids, they were 8 and 5 when I started getting sick.

According to the TWC website, the mission of the organization is to meet the self-defined needs of women and their families living with and at risk for HIV/AIDS, reducing barriers to care, and strengthening their network of support services. The organization is a nonprofit 501(C) 3 organization dedicated to meeting the needs of women with HIV/AIDS. Founded in 1993, the TWC mission begins with the premise that women with HIV/AIDS must be involved in every aspect of health care service delivery and their empowerment through peer support must be encouraged. Services begin at the very moment of diagnosis and continue throughout the continuum of this disease in order to help women access care and services. It is a holistic approach, designed to respect and honor the complexities of women's lives.

The women in the support group met to discuss a myriad of issues that included disclosure of their HIV status to family and friends and medication adherence. The exact ages and backgrounds of the women included in the sample were not collected due to confidentiality issues surrounding the women's HIV status. Twenty percent of the women in the groups were in their mid-30s and 80% were at least 40 years of age. The women were primarily from Washington, DC, and most of the women had contracted HIV through heterosexual contact with a boyfriend, casual sexual partner, or husband. Some of the women in the group were recovering drug users and had contracted HIV through intravenous drug use. Many of the women were mothers and have children who are HIV negative. Most of the women were unemployed, received monthly disability assistance, and had attended programs and support groups for at least three years. Lastly, 90% of the women were African-American and 10% were Hispanic. The names of all of the women involved in the study were changed to protect their identities.

Data Collection Procedures

Data was collected from February 2008 to April 2008. All of the interviews took place at TWC, where the women participated in support groups. The data was collected through a variety of methods, including two interviews with staff members of the organization and several direct observations of support group meetings, staff workdays, and a poetry event. The direct observations occurred during the group meetings where the women would meet for support. I observed the women's interpersonal communication amongst each other as well as the conversations they had about their lives, families, and HIV.

Data were collected on women's attitudes about being HIV positive, perceptions of HIV stigma, disclosure of HIV status to family and friends, routes of transmission, and other themes, such as medication adherence. Examples of questions that the women and staff were asked include: "How does it feel to be HIV positive?" This question was meant to evoke responses related to emotions, meaning, and the larger context of being HIV positive. Similarly, questions such as "What is your daily routine?" and "How did you get infected?" are meant to gain further insight into the lives of women who are HIV positive. In addition to these contextual questions, I queried the women about issues such as stigma, disclosure, and medication adherence to gain an overall picture. Examples of these questions include "How do people cope with learning you're HIV positive?" and "How do you handle your medication?" Prior to all observations and interviews, the women were given consent forms to complete and were instructed that they could leave the study at any time without fear of losing the services they were receiving at the organization. Interviews were conducted using an open-ended format to allow the women to guide the discussions during the focus groups and individual interviews. This study was submitted and approved by the Institutional Review Board for the Protection of Human Subjects at the University of Maryland, College Park.

The support group and key informant interview notes were taken in shorthand. To maintain the anonymity of the participants, pseudonyms were used. When meeting women for the first time in a group session, I scheduled additional individual follow-up interviews in order to have more in-depth discussions.

One question asked to participants in the short interview for the group interviews was "How does it feel to be HIV positive in Washington, DC?" This question was used to elicit emotions, meaning, and the larger context of being HIV positive. Similarly, questions such as "What barriers to services do you experience?" and "What social services would you like to receive in the future?" were meant to gain further insight into the lives of these women. These open-ended questions were designed to encourage further conversation and to obtain more details about the women's lives, such as the barriers that affect utilization of available social services and HIV treatment medication. In addition to these contextual questions, the women were queried about issues such as stigma, disclosure, and medication adherence to gain a more complete picture of their lives. Examples of these questions included, "How do people cope after learning you are HIV positive?" and "How do you handle your medication adherence?" The protocol that I used to interview staff was significantly more in-depth than the questions asked of the women participants and contained questions such as, "How did you become interested in working with people who have HIV/AIDS in Washington, DC?" and "What should people know about HIV prevention and stigma for women living in Washington, DC?" The questions also assessed the staff member's self-awareness about HIV and how it affected their own personal and professional relationships.

The questions were derived from a combination of inductive and deductive reasoning. Deductively, I used situations that the staff of the organization had encountered from working with the population in the past to guide them and allow for the formulation of questions that would elicit substantive responses from the participants. Inductively, from listening to the women in the group session and following the flow of the conversation I was able to interject questions into the conversation to elicit responses

from the participants. The questions were interjected into the conversation to provide opportunities for the woman to expand on what she was feeling during the conversation.

Data Analysis

The data was analyzed using ATLAS.ti.5.2, and was coded according to major themes that emerged from the focus group discussions and individual interviews. Daly states that open coding is a way of opening up the data in order to explore what it means...as our analysis depends through the process of coding transcripts, we begin to see similarities in our participants descriptions of events and activities (Daly, 2007). The themes that emerged were stigma, feelings of self-worth, modes of transmission, medication adherence, disclosure, social service needs, and benefits derived from attending the organization. Interviews were transcribed verbatim and were coded around these major themes. Interviews were initially open-coded and then coded more in-depth, using selective and axial coding to identify subthemes. Additionally, memos were written over the course of the field placement on emerging concepts, strengths and weaknesses as a researcher, and selective coding. Data from the women and staff were analyzed separately to allow for distinct themes to emerge based on the individuals' experience with providing or receiving social services.

Data Quality

There were many aspects of data quality that were used to validate data collected. Some of the strategies utilized were: triangulation, prolonged exposure in the field, peer debriefing, and member checks. Triangulation refers to the use of multiple data sources to understand the overall picture. Triangulation was used by referring to journal articles, books, websites, reports, and national health data to understand the implications of HIV in African-American women. Specifically, a Pub Med search was conducted for relevant journal articles using the keywords HIV/AIDS, African-American women, health disparities, and social service needs. From this initial search the researcher was able to narrow down the articles that were relevant for inclusion.

By utilizing multiple sources of data and research methods, I aimed to reduce the likelihood that the information collected or coded was subject to researcher bias, or systematic errors. Secondly, through the use of prolonged exposure, I was able to build a rapport with the women and staff and establish credibility as a temporary member of their community. The women's levels of comfort gradually increased as more time was spent in the field as a participant and as an observer. Through the use of peer debriefing in small group workshops, I was able to gain further understanding of the dimensions and directions of my research question. This process encouraged me to think critically about what I hoped to gain from the field experience, while at the same time giving insight into sub-themes that were emerging during my time in the field. Finally, by utilizing member checks with women, I further validated the data and ensured that I was accurately capturing the women's stories. By conducting member checks with the women, I provided authentication for their stories and personal experiences. The process that I undertook to guide the research process and provide validation to the women's experiences is defined as reflexivity. Daly defines reflexivity as the ways in which a

researcher critically monitors and understands the role of self in the research endeavor (Daly, 2007).

Results

Issues that have come out of the research have been related to the women's childhood experiences and the fact that some of them were abused and did not have family members from their childhood as part of their support group. The recurring theme of child and sexual abuse was discussed in the groups and some of the women had never received therapy for it. For some women, this was the beginning of their dependency on drugs and alcohol. A competing theme that goes against this thought is centered on women from stable households who got addicted to drugs and alcohol and also ultimately ended up HIV positive. These women who had not been sexually abused had lives that directly contrasted the tales of abuse previously heard from sexually abused women about how they ended up on drugs.

Stigma and Social Support

The emotional and personal lives of the women have been severely impacted through the internalization of the stigma surrounding HIV/AIDS. One surprising theme with all of the women in regards to internalizing the stigma associated with the disease was that it did not matter how the women were infected, the stigma was still attached to the disease. For example, when speaking with a woman who had gotten infected by her husband, she continued to blame herself, although her husband was bisexual and had gotten infected by a man. In this situation, the husband put his wife unnecessarily at risk through his unprotected sexual relationships. The woman also informed the researcher that she had never really seen a therapist to deal with these issues and it took her 16 years before she was able to be civil with her ex-husband. Additionally, the woman's child died from complications related to being HIV positive, which is something else the woman did not forgive herself for:

I had recently been married to my 2nd husband Michael when I was diagnosed. At the time there were a lot of misconceptions about HIV transmission. I had two kids, Gary and John at the time. My 1st husband Geoffrey died from hypertension and high blood pressure. I also miscarried with twins around this time. I kept asking myself, how did I get it? I thought only gay people got it. My marriage to my 2nd husband lasted only 2 months, I got married and in January of 1994 and left him on July 3rd. I also had a child at a later age, I was 38 years old. Due to being older, I took a lot of tests because I was a high risk pregnancy, and that is how I found out I was HIV positive. The physician walked in and told me that I was HIV positive and walked out. I was stunned when I left the Doctor's office, and for a while after that I pushed my children away because I wasn't sure how the disease was transmitted. I wasn't educated about HIV.

A similar theme of shame and guilt was seen in the case of a woman who was infected by using intravenous drugs. During the group sessions, the woman was very open about her rampant drug use, and how it caused her to lose everything, including custody of her child, her house and the support of her family members. This woman also spoke about how she used to shoot drugs after people who had shot drugs, with their blood still in the syringe. The woman spoke about how being HIV positive changed her life and how she has felt ashamed since she became positive. She has since stopped using drugs, but always reminds herself of her troubled past. A recurring theme with this woman was to bring the group back to her situation and how she got infected. She spoke about it as if she was embarrassed to be who she is because of her past. There were many times during the focus group when other participants would speak about their stories of transmission, and the woman would say, "At least you didn't get infected using some dirty-a** needle." This particular woman also has serious reservations about disclosing her status to other people who are not HIV positive. She believes that people who are not positive, or haven't used drugs cannot possibly relate to her struggle, and that they will judge her:

I didn't ask for this! People have to remember that not everyone who is infected has gotten it from doing something dirty and illegal. Some of us are just regular people. I have to reach down and know myself and am OK with that. My 1st time telling someone (I was positive) I could have won an Oscar for my performance. I was sweating, and crying. When I told him he didn't even get mad. He said, what are you worried about? I have a gut feeling for who I tell and don't tell. Some co-workers and managers at work know, even some random people know. I've been positive for 27 years, and when I tell people I trust them to be confidential. When I had sarcoidiosis I looked like death. I was skin and bones. People would whisper and ask if I had HIV.

This quote referenced above also brings to light the negative image of people who have HIV, how they contracted it, and the stigma attached to the disease. Although some women do get infected from intravenous drug use, Jane was simply a woman who had heterosexual sex with her partner.

The next quote came from another participant. Lynette. The response she gave was related to the question about her thoughts on stigma in the HIV community.

Stigma is prejudging – people think that it's something you did to deserve the disease. This invalidates people- no one deserves HIV, regardless of their behavior. HIV positive people are judged so harshly, and it can be really hard when you are ostracized by someone who loves you, or is supposed to manage your care. The reality is that I can't hurt you, but you can take me out with one sneeze.

The following quote further emphasizes the burden of stigma:

I have faced stigma in my daily life through personal relationships. I have dated guys and disclosed to them, but it always made me so uncomfortable that for a while I stopped dating and wouldn't put myself in socially awkward situations where some people may or may not know my status. There are some people in my family, especially people back home that don't know my status. **It's not like I come out and say hi, I'm Karen and I'm HIV positive.** I've lost a lot of friends due to HIV. When you're living in this life, you create a whole new community. My whole network now is people who are familiar with the disease, everyone I am close with either lives or works with this disease. Sometimes I feel as if it's all I can talk about.

This quote gave insight as to how difficult dating must be for someone who has HIV. Although HIV has been around for a long time, people still don't know the rates of transmission, and even worse, they are scared of getting infected by showing affection to someone who is HIV positive. It is as if people are afraid they can contract it from hugging or kissing the infected person. "I have faced stigma in my daily life through personal relationships. My sister's husband would throw dishes away that I used because I was HIV positive. No one wanted to touch or hug me because of my status."

Disclosure

Disclosure played into the personal lives of women in a very difficult way. The women that were interviewed and observed during the group expressed a sense of trepidation in regards to disclosing their status to people around them who may judge them after finding out their status.

I can't relate to what Jane is saying because I don't have any social support from my friends, male or female. No one except my family knows about my status and I'm embarrassed to tell them the details of what I go through. Maybe I should just move away.

This quote demonstrates the desperation that some of the women feel in regards to disclosure. Later on in the same group session, another woman expressed frustration about her friends inquiring into her health and well-being, and at the same time not being able to express herself to them:

I have people that I've been friends with since 1971 that I haven't told. I got Hep and my friends were worried that I was losing weight. They asked my daughter what was wrong with me and she wouldn't tell them, it's not her place to tell them. I'm so mad at them for asking her about me and one of them even had the nerve to ask my daughter if I was HIV positive!

These quotes taken from the women illustrate the many levels of hiding and fear that the women live in, when people that are closest to them are unable to be a support for them in regards to their healthcare or medical needs.

Medication Adherence

Another issue that impacts the women's personal lives and medical situations is noncompliance with medication. Some of the women in the group have been positive for a very long time, and expressed similar themes of being tired of taking their medication. The women talk about AZT, and the seriousness of the side effects which has turned them off trying some of the newer medications:

My life with HIV is managed by my medications. I am constantly affected by the side effects. Some of the side effects that I have to manage are diarrhea, nausea, neuropathy in my legs and feet. I also have to deal with hair loss and physical symptoms. I hate looking at pictures of myself because I don't like looking at myself, I don't look like me.

An additional comment on medication adherence, and coping with HIV:

I have always been on meds, when I was first diagnosed I was 80 pounds and had no T-cells. I was diagnosed in 1986. AZT was approved in 1987 and I've been on meds most of the time during my diagnosis. I struggle with adherence, I skip meds sometimes. The combos change and some of them don't work so I switch them from time to time. I've been on my current regimen for the past 3 years.

A theme that emerged from the group was the notion of being "undetectable". Undetectable can be defined as having a viral load of HIV so low that it is virtually undetectable. It is ultimately misleading because people think that they have been cured, or that being in this status allows them to carry on unsafe behaviors, or negate the use of future medications. This concept is also problematic because although the viral load is undetectable in someone's body, HIV still exists and can continue to replicate itself. Therefore, for some of the women who are in this stage, there is an air of invincibility. The women made references to themselves and their health as if they didn't have HIV anymore, which could lead to dangerous sexual health decisions. For the few women who were in this situation, it was used as a chance to separate themselves from the rest of the group and seem somewhat "healthier" or better than the women who had higher viral loads. This again relates back to the stigma that surrounds HIV, in that certain women have internalized the stigma to the point where they use it to increase their own self-esteem.

Discrimination

Discrimination is a major theme under the guise of internalizing stigma because the women feel that they are discriminated against and treated unfairly when they receive services such as medical and social services. The women expressed anger,

disappointment and hurt when dealing with people in their families who are ignorant about transmission methods of HIV, and people in general who regard them with disdain, or as being a dirty or bad person because they are positive. The women repeatedly raised the point that they felt the only reason that there is a stigma attached to HIV is because it is generally related to sex or drugs, both of which are taboo. For instance, many of the women think that if HIV was similar to diabetes or hypertension, then there would be no problem in treating or educating people on the transmission of HIV. This can also be seen in the case of service delivery with organizations around the city. The women have spoken of their status being mentioned casually in front of people they didn't want to know by their doctors and other situations where the women's needs were not met and confidentiality was not enforced. The constant lack of confidentiality takes its toll on the women's feelings of self-worth, and over time can make the most confident advocate unsure of her worth in terms of being HIV positive. A quote from a staff member of TWC further emphasizes this point:

For the clients we see and their families, HIV is just another thing on their plate. They are also dealing with homelessness, drugs, breast and cervical cancer, diabetes, and high blood pressure. When they are diagnosed with HIV, it's like...ok, so what? HIV is not a priority in women's lives, it's a shock but they don't have the luxury of time to dwell on HIV. Women are not equipped to deal with this, women get pushed to the back burner, and there is no time for you. My life is no different from theirs...the shock value is lost because women have so much to do. Women are becoming more and more infected and yet unaffected by this disease.

A quote from a participant regarding discrimination:

I have been discriminated against ever since I found out I had HIV. I remember laying in the hospital bed when I was admitted for pneumonia and having nurses not want to touch me or work with me. This was back in the day when HIV first came out and people did not know how to work with it. But that experience is still in the front of my mind. That is not something you can easily forget. It stays with you.

Discussion

The disproportionate effect of HIV/AIDS on African-American women warrants the development of effective strategies to prevent new HIV infections, to detect HIV infections early and to assure adequate treatment for African-American women who are HIV positive. The increasing number of African-American women who are successfully living with AIDS is largely due to advances in the medication options and treatment plans that women have. The early diagnosis of HIV infection would enable African-American women to take full advantage of antiretroviral therapies and prophylaxis for opportunistic infections, both of which can forestall the development of AIDS-related symptoms and decrease the morbidity and mortality associated with HIV infection (Whitmore, 2005).

Research findings suggest that there are potentially negative consequences of being in social relationships in which stigma and embarrassment inhibit women from taking their medications in the presence of others (Alonzo & Reynolds, 1995). Women who have not disclosed their HIV status to their families or friends may find it difficult to adhere to HIV medication regimens while in the presence of family members, or even in the privacy of their own homes (Edwards, 2006). Consequently, rather than publicly disclosing their status and risk social isolation, women often put off taking their medications. Another issue of note is that feeling unloved and unsupported was a social and emotional barrier to medication adherence for the women. Many of the women expressed that the absence of love and social support from those around them affected their medication adherence.

The results of the current study indicate that there are many layers of issues that HIV positive women face on a daily basis, and the research captures more of their daily barriers and obstacles. The women in the groups dealt with the daily stressors of child and sexual abuse they had endured from a parent or trusted person, the stigma and lack of social support in dealing with their diagnosis, and the shame and guilt associated with an HIV positive diagnosis. Additionally, the women in the group suffered from issues surrounding disclosure of their HIV status to co-workers, family, friends, and significant others. The women carried layers of guilt, stigma, and disclosure on their shoulders, and for many the thought of seeing a mental health provider was out of the question due to personal issues or financial constraints. Finally, for women who had come to terms with their diagnosis, the concept of being undetectable with regards to HIV gave them a cautious optimism, and something to be happy about.

Conclusion

By observing women and hearing about their struggles, fears, and thoughts, as shared in a supportive group setting, the researcher was able to identify some of the factors that may prevent women from accessing vital social services. This research is not without its limitations. The research was conducted in one setting with a small sample size. Biases may have been introduced in the selection process because women who worked in the evenings and were not available to attend groups may have offered different insights from the women in the sessions.

Consequently, further research should explore the best avenues for HIV positive women to express themselves and advocate for themselves, thus increasing exposure and awareness about HIV and validating the women's needs. Future research in the area of mental health and HIV should include resources to help women deal with issues that have been suppressed since childhood is warranted. As HIV and AIDS continue to impact women of color in Washington, DC, continuous research is necessary to further investigate HIV and clinical care to help people obtain more positive health outcomes. However, emphasis also needs to be applied with current knowledge about HIV prevention and treatment in women by enhanced usage of available health services, to include greater use of antiretroviral therapy options, depression treatment, facilitation of educational efforts, and increased social support to reduce needs that prevent women from taking control of their HIV prevention and treatment (Hader, 2001).

Furthermore, most HIV prevention programs address only consensual sexual practices and fail to address the psychological consequences of early abuse on sexual decision making. Findings from Wyatt, et al. suggest that sexual abuse, incidents of attempted and completed rape and physical abuse in childhood and adulthood conferred additional risk for HIV infection. Although additional attention is currently being focused on HIV exposure prophylaxis when persons who are HIV positive suspect that they have been re-exposed to HIV, less attention has been given to the possibility that women who are already infected with HIV may also be at risk for re-victimization through coercion and rape. More research is needed on the issue of the causal relationship between violence, victimization and HIV. It is possible that some of the same factors that increase HIV risks for women also place them at risk for nonconsensual sex (Wyatt, 2002). Coercive and abusive relationships limit a woman's ability to effectively negotiate safer sex and also may be indirectly related to involvement with multiple partners or "survival sex" for financial stability. Greater economic dependence on partners can limit women's personal control over HIV risk practices (Amaro, 1995).

In conclusion, the research that was conducted with women at TWC will further illustrate the diverse issues faced by women of color who are HIV positive in Washington, DC. The women represent a segment of the population that are in dire need of health services, treatment and care options, and maintenance programs for people who are HIV positive. As evidenced, there are many factors that lead to a woman being at risk for infection of HIV, and these include but are not limited to: heterosexual sex, intravenous drug use, unstable housing situations, and having sex with a man who is bisexual. This research will provide a foundation for future policy aimed at reducing the disparities in HIV, related to the prevention and transmission of the disease, and at the gender inequalities that disproportionately affect women.

References

- Adimora, A. (2005). Social context, sexual networks and racial disparities in rates of sexually transmitted infections. *Journal of Infectious Diseases*, 1(191), S115-S122.
- Alonzo, A. A., & Reynolds, N. R. (1995). Stigma, HIV and AIDS: An exploration and elaboration of a stigma trajectory. *Social Science and Medicine*, 41(3), 303-315.
- Amaro, H. (1995). Love, sex and power: Considering women's realities in HIV prevention. *American Journal of Psychology*, 50(6), 437-447.
- AVERT. (2009). *Averting HIV and AIDS*. Retrieved from <http://www.avert.org/usa-race-age.htm>
- Buseh, A. (2006). Constrained but not determined by stigma: Resistance by African American women living with HIV. *Women and Health*, 44(3), 1-18.
- Daly, K. J. (2007). *Qualitative methods for family studies and human development*. Thousand Oaks, CA: Sage.
- DC Appleseed. (2005). Solving DC problems. Retrieved from <http://www.dcappleseed.org>
- DiStefano, A. & Cayetano, R. (2011). Health care and social service providers' observations on the intersection of HIV/AIDS and violence among their clients and patients. *Qualitative Health Research*, 21(3), 884-899.

- Edwards, L. (2006). Perceived social support and HIV/AIDS medication adherence among African American women. *Qualitative Health Research, 16*(5), 679-691.
- Fears, D. (2005, February 7). US HIV cases soaring among Black women. *The Washington Post*. Retrieved from <http://www.washingtonpost.com>
- Hader, S. S. (2001). HIV infections in women in the United States: Status at the millenium. *Journal of the American Medical Association, 285*, 1186-1192.
- Leigh, B. S. (1993). Substance use and risky sexual behavior for exposure to HIV: Issues in methodology, interpretation, and prevention. *American Psychology, 48*(10),1035-1045.
- Participant observation. (2012, October 29). In *Wikipedia, The free encyclopedia*. Retrieved from http://en.wikipedia.org/w/index.php?title=Participant_observation&oldid=520446509
- Whitmore, S. S. (2005). Epidemiolgy of HIV/AIDS among non-Hispanic Black women in the United States. *Journal of the National Medical Association, 97*(7), 19-24.
- Wyatt, G. E., Myers H. F., Williams, J. K., Kitchen, C. R., Loeb, T., Carmona, J. V., Wyatt L. E., Chin D., & Presley, N. (2002). Does a history of trauma contribute to HIV Risk for Women of Color? *American Journal of Public Health, 92*(4), 660-665.

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